**The Governor's Healthcare Reform Implementation Council ACA Medicaid Reform Testimony**

The Affordable Care Act (ACA) is both a great boon and a great strain to state government, particularly for Illinois. As the state faces high unemployment rates and nearly a $14 billion deficit, allowing hundreds of thousands more Illinoisans to receive Medicaid assistance is a great advantage for people with low incomes as well as people with disabilities. The unemployment rate within the disability community in Illinois hovers around seventy percent, and this has been the norm long before our current economic downturn. Combining that fact with higher unemployment among the nondisabled community adds a great deal of stress to an already overburdened healthcare system.

The other, possibly even more daunting situation facing Illinois government is the extraordinarily high institutionalization rate for people with disabilities in the state. Though advocacy efforts have attempted to change this mindset over the years, Illinois still ranks near the bottom of all states in the country in its use of state operated developmental centers (SODCs), nursing homes, and large ICF/DD. Illinois ranks 51st in the nation when it comes to spending for small community living opportunities for people with disabilities. The state ranks 47th nationwide in community services spending but ranks an inglorious fifth in the country on spending for SODCs. Illinois annually throws millions of dollars at state run institutions, spending on average $166,000 per year on each resident, when the cost of providing services for persons living in the community averages closer to $50,000 annually.

Some may ask what these specific figures have to do with the ACA. My response is that when asked what changes Illinois needs to make to improve the quality of long-term care in the state, I believe we should stop throwing good money after bad. The ACA is pushing states in the direction of less reliance on institutionalization and much more emphasis on home and community-based services. Illinois needs that exact kind of change to guarantee the implementation of healthcare reform. For decades, the state has taken the easy road of institutionalization to bypass the difficult decisions that come with integrating people with disabilities into the community. The ACA has done what Illinois legislators and policymakers have ignored far too long, and that is forcing the state's hand into acknowledging what is a higher priority—institutionalizing people with disabilities because that seems the easier solution or working more diligently to allow people the choice of moving into the community.

Choice is truly the central theme of all the questions asked by this Council. The independent living philosophy values individual choice foremost in the lives of people with disabilities. The choice to live in the community is fundamental to an individual's ongoing overall health. The choice of doctors and specialists who provide care to people with disabilities is equally critical in the overarching theme of healthcare reform. As long as Illinois retains the mindset that SODCs provide adequate living arrangements for people with disabilities, the state will not move forward. If Medicaid managed care becomes the norm in Illinois with HMOs potentially putting profits before people, the state will not move forward. There are tangible ways to assure the letter and spirit of the ACA reach fulfillment in this state, and that comes through putting consumer choice ahead of bureaucracy, policy, profit, and especially politics.

No one with knowledge of the situation would say it is reasonable to close all Illinois' SODCs immediately. Transition takes time, but it must begin before it can reach any semblance of fruition. States across the country have eliminated institutions completely by establishing group homes and CILAs in the heart of the community. Before Illinois can take the actions they ACA has put forth for it, regarding more home and community-based services, its elected officials must focus on establishing the necessary community services and supports. Therefore, a tangible change in the approach Illinois takes to long-term care is providing more accessible and affordable housing. You cannot expect people to move out of institutions or even contemplate such a move, if they feel they

have nowhere to go once they are "on the outside." A recent study from the University of Colorado showed Illinois ranks worst in the nation when it comes to housing for people with disabilities. A result like this is unacceptable. An effort to change this culture and provide adequate housing would require an initial outlay of several millions of dollars, but it would also create jobs, provide housing, and boost an otherwise sagging Illinois economy. Moreover, studies have shown people who live in the communities as opposed to institutions have better overall health outcomes, including mental health.

There is also a tangible way to guarantee transparency and consumer choice in what increasingly seems like a statewide Medicaid managed care system in the future. First, people with disabilities and seniors must be involved in the contract negotiation process to make their concerns heard and force both the state and HMOs to act in good faith when implementing consumer choice-driven aspects of the contracts. However, advocacy and the presence of advocates must not end when the contracts are signed. There must be an independent oversight committee, comprised of advocates, providers, and other interested and astute individuals, to act as a watchdog over both the state and the HMOs. There are too many examples from numerous other states delineating how Medicaid managed care has worked as a complete failure with HMOs receiving far too much profit and the states providing far too little oversight. Illinois needs to avoid this trap before the system begins. There are examples to which the state can turn to avoid the pitfalls of California, Florida, and Wisconsin. Consumer choice is the key, and providing a consumer voice in the overall process of creating such a vast and uncharted system allows Illinois to show in concrete terms its commitment to better healthcare and better lives for people with disabilities.

These are only two problems and two potential solutions in the Herculean effort of implementing the ACA accurately, completely, and equitably. There is much more than can be discussed in only one hearing. However, it is essential for this Council to understand the fundamental principles behind the ideas that guide people with disabilities and the disability rights movement. Consumer choice, independence, freedom to live where you choose, and access to healthcare not mandated by sometimes unknowing insurance companies only begin to scratch the surface of the many issues people with disabilities find concerning in Illinois' current fiscal and healthcare environments. Yet, even as we bring these concerns before you, we also have hope the ACA will develop into everything the federal government intended it to be. We are now beginning to crack open the door and see what lies behind the term "healthcare reform." Now, we all must act in ways that reach the goals of the ACA and strive for means that go beyond the Act's intent into another area where integration of healthcare meets integration into the community. That is our truest and most important goal.

**Tyler D. McHaley**
**President Springfield Area Disability Activists**
**234 Norwalk Rd.**
**Springfield, IL 62704**
**Cell: (217) 899-5015**
**E-mail: Tyler.Mchaley@gmail.com**
**www.disabilityactivists.org**